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## Death—whose decision? Physician-assisted dying and the terminally ill

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The first person to choose a statutory-sanctioned death with physician assistance was Bob Dent of Darwin, Northern Territory, Australia, who died September 22, 1996. This was possible under the Rights of the Terminally Ill Act, which had become effective in the Northern Territory July 1, 1996. By chance, one of us (S I F) was in Australia and observed the resulting furor, which ran the gamut from approval to vociferous condemnation.

In particular, we were struck by a letter dictated by Bob Dent to his wife that outlined why he was making this choice and pleading that this “most compassionate legislation in the world be respected.”<sup>1</sup> He described an incontinent, pain-wracked, totally dependent existence that was exacerbated by watching the suffering of his wife as she cared for him. He was “immensely grateful” that he could end his life in a dignified and compassionate manner. In addition, he asserted

which I don’t subscribe) to demand that I behave according to their rules until some omniscient doctor decides that I must have had enough and increases my morphine until I die?

In this article, we comment on some of the legal and ethical ramifications of this complex situation. Only physician-assisted death for competent, terminally ill persons will be discussed. Our society believes in the principles of individual autonomy, liberty, justice, and democracy. We consider that the interaction of the traditional value-of-life ethos, certain religious beliefs, and the stark realities of medicine at the end of life has most commonly resulted in an arbitrary “line in the sand” that is inconsistent with these principles.

### THE LEGALITY OF ACTIVE EUTHANASIA

Thirty-four states of the United States, including Washington and Oregon, have statutes explicitly criminalizing

[T]he Church and State must remain separate. What right has anyone because of their own religious faith (to

assisted suicide. Oregon, as the result of a citizen initiative ballot (Measure 16), has allowed a specific departure by permitting physician-assisted death under very restricted conditions. However, because of court challenges, initially no legally sanctioned physician-assisted death occurred. In May 1997, opponents of the law successfully persuaded the lower house of the Oregon Legislature to return Measure 16 to the voters for possible repeal. The principal opponents to Measure 16 are Physicians for Compassionate Care, whose leader is a devout Catholic.

In February 1997, the Ninth Circuit Federal appeals court upheld Measure 16 but allowed a stay to remain in effect until a ruling by the US Supreme Court. The Supreme Court ruled in June 1997 (considering also a similar opinion rendered by the Second Circuit Federal appeals court) and effectively refused to grant Americans a constitutional "right to die." "However, their ruling did not preclude states from passing laws that would establish such a right: in fact, five of the nine justices suggested they might support such a claim in the future."<sup>2</sup> In November 1997, 60% of Oregon voters rejected the attempt to repeal Measure 16. The federal appeals court lifted the stay that barred implementation of the law. Both proponents and opponents of this "only one of its kind in the world" statute predict "the adoption of similar measures in other states."<sup>3</sup>

A recent report on the first 14 months of experience with the Oregon Death with Dignity Act draws some preliminary conclusions.<sup>4</sup> Fifteen persons, 13 with cancer, have used the act to end their lives, an estimated 0.2% of those eligible. Loss of autonomy and of control of bodily functions, rather than pain, were apparently the most frequent motivators. Unmarried patients were disproportionately represented; otherwise, demographic factors and education were not predictive. No obvious abuses of the law or unintended consequences have occurred so far.

In Australia, the Northern Territory legislation was short-lived. In March 1997, the federal parliament effectively repealed the "state" legislation by passing in the Australian senate the Euthanasia Laws Bill, commonly known as the "Andrews Bill" after its unapologetically doctrinaire architect. A member of the Australian senate, he is also described as a "father-of-five and lawyer in bioethics."<sup>5</sup> However, draft legislation in the state of South Australia, if passed, will challenge this federal law. Between September 1996 and March 1997, four competent terminally ill persons were able to exercise the right to physician-assisted death. Both the Oregon and Northern Territory laws had exhaustive provisions designed to safeguard the integrity of the legislation and prevent abuse.<sup>6,7</sup>

Just how did society arrive at this impasse where we heatedly debate right-to-die legislation? In the past, most people died relatively quickly as a result of accident or illness. The rapid increase in medical knowledge, technol-

ogy, and intervention often allows those who are terminally ill to linger. Despite the advances in palliative care, the death process is too often protracted, painful, and undignified.

Therefore, it is hardly surprising that in both the United States and Australia, public opinion polls have consistently supported physician-assisted death.<sup>8,9</sup> In Oregon in a February 1997 poll, 61% answered yes to the question, "Shall the law allow terminally ill adult patients the voluntary informed choice to obtain a physician's prescription for drugs to end life?" An indication of social division even in Catholicism is that 50% of the Catholic voters answered yes to the same question.<sup>10</sup>

It is difficult to generalize on physician opinion with regard to physician-assisted death. Investigation of current attitudes reveals a complex situation. Recently, the Oregon Medical Association changed its formerly neutral stance and specifically opposed Measure 16. This may be a reflection of the intense lobbying by the Physicians for Compassionate Care because previously two thirds or more of Oregon physicians surveyed favored a patient's right to obtain a physician's help in hastening death in certain circumstances.<sup>11</sup>

In Australia, of 1,268 physicians on the New South Wales state register surveyed in 1994 by Baume and O'Malley, 59% answered yes and 3.3% "it depends" to a question whether they favored physician-assisted death.<sup>12</sup> In 1995 Baume and colleagues looked at the question of religious affiliation and the practice of euthanasia and found that attitudes varied significantly according to religious affiliation, with "nontheists" most sympathetic. The "theists" who reported a Protestant affiliation were intermediate in their attitudes. Perhaps most interesting was that 18% of Catholic medical practitioners who responded recorded that they had taken active steps to bring about the death of patients when requested.<sup>13</sup> In Michigan, the most important personal characteristic that defined physicians' views against "assisted suicide" was a strong religious affiliation.<sup>14</sup>

## DISCUSSION OF PRINCIPLES

Whenever these issues are debated, certain terms keep appearing: "autonomy," "liberty," "justice," and "best interests." For a nonexpert to have any hope of understanding these terms, it is necessary to look at current medical reality. The Ninth Circuit Court of Appeal judges observed that "today, doctors are generally permitted to administer death-inducing medication, as long as they can point to a concomitant pain-relieving purpose."<sup>8(p822)</sup> Physicians are aware that the medication may have a "double effect," a term that "originates in Roman Catholic moral theology, which holds that it is sometimes morally justifiable to cause evil in the pursuit of good."<sup>15(p316)</sup>

The American Medical Association appears to sub-

scribe to the euphemism of double effect with the following statement<sup>8(p823)</sup>:

The intent of palliative treatment is to relieve pain and suffering but the patient's death is a possible side effect of the treatment. It is ethically acceptable for a physician to gradually increase the appropriate medication for a patient, realizing that the medication may depress respiration and cause death.

Does double effect mean double standard? The debate seems to be about who gets to have input into decisions about death, and so far it appears to be the "omniscient doctor" referred to in Bob Dent's final letter. We can only consider a sampling or snapshot of an ethically and legally complex and confused situation but will nevertheless attempt to reach some understanding. Several ethical principles in our society bear on this discussion.

### Liberty and individual autonomy

In the United States, autonomy or the principle of individual decision making is highly valued. The "liberty interest," a person's right of choice, is guaranteed in the Fourteenth Amendment to the United States Constitution. Thus, the issue of physician-assisted death is as much about control as about dying. Does a traditionally paternalistic medical profession continue to have the ability to override a competent, terminally ill patient's wishes and to insist on the right to "know best" in this crucial end-of-life decision? It appears contradictory that in the United States, at least, a competent, terminally ill patient has the right to make a legally binding advanced directive in anticipation of the inability to choose withdrawal of treatment (eg, gastrostomy tubes) but is not permitted to hasten death by means of additional medication given with physician advice or assistance in the final stages of illness.

The Ninth Circuit Court judges were not impressed by the argument that physician-assisted suicide is different in kind, not degree. They drew an analogy between the withdrawal of a gastrostomy tube so that the patient starves to death and prescribing analgesics to relieve pain when these also depress respiration and result in the patient's death. In the former, the cause of death is starvation, and in the latter, the provision of analgesics. In neither case does the patient die of the underlying disease or injury. Addressing the issue of physician-assisted suicide, the judges stated<sup>8(p824)</sup>:

We see no ethical or constitutionally recognizable difference between a doctor's pulling the plug on a respirator and his prescribing drugs which will permit a terminally ill patient to end his own life. . . . To the extent that a difference exists, we conclude that it is one of degree and not one of kind.

These judges clearly recognized that some, perhaps many, physicians discreetly help their patients to die and acknowledge privately that this is so.

If autonomy is a highly valued principle, it is logical that patients, especially, and possibly family, should have the right to participate in all end-of-life decisions. Why should the most crucial end-of-life decision be arbitrarily barred? The criminalizing of physician-assisted suicide is effectively a prohibition of suicide for many terminally ill patients. The judges held that the liberty interest should allow competent, terminally ill patients the right to choose the time and manner of their death. They considered that adequately rigorous safeguards could be implemented in the decision process to prevent abuse. "We believe that the possibility of abuse . . . does not outweigh the liberty interest at issue."<sup>8(p837)</sup>

### Justice

To most people, medical justice means the fair and equal treatment of patients. The current situation has elements of injustice. For instance, often competent, terminally ill patients are too debilitated to take active steps to end their suffering should they choose to do so. As it is an offense in most states for anyone to assist a suicide, many terminally ill patients are effectively denied private options available to those who are not terminally ill.

There is a perception that any change in the status quo will inevitably lead to widespread abuse. The rationale of this perception is hard to follow because those who hold this view have not demonstrated a necessary cause-and-effect relationship.

### Democracy

More than 20% of physicians in both the United States and Australia admit to taking deliberate action to end the lives of particular patients. This situation almost certainly disproportionately benefits more privileged persons in society because they are much more likely to have a relationship of trust with a medical practitioner who will discreetly alleviate their suffering. The former Northern Territory Chief Minister, when commenting on the demise of his legislation, observed that the senators who voted for repeal "belong to that privileged, wealthy group who have access to voluntary euthanasia themselves."<sup>16</sup>

### Family autonomy

Another area that appears to contradict "best interests" is the effect of terminal illness on patients' families. First, how people die irrevocably influences how we remember them. Surely few would wish to be remembered or to remember a loved one as helpless, incontinent, pain-racked, or sedated, as was graphically expressed in Bob Dent's final letter. Currently it is illegal to assist suicide in two thirds of the United States. Consequently, thinking



people who are in unbearable pain die alone (if they commit suicide) because they do not want to put loved ones at risk.

For instance, a leading supporter of the Oregon Death with Dignity Act is prompted in part by the fact that his wife of 49 years committed suicide alone, which resulted in his subsequent investigation by the coroner and police.<sup>17</sup> When they were considering the possibility of this kind of investigation, the Ninth Circuit Court judges observed that almost all who agreed to assist the dying avoided prosecution but would “likely suffer pain and guilt for the rest of their lives.”<sup>8(p836)</sup> Likewise, those who did not assist often question whether they should have tried to spare their loved ones. “This burden would be substantially alleviated if doctors were authorized to assist terminally ill persons to end their lives and to supervise and direct others in the implementation of that process.”<sup>8(p812)</sup> Indeed, physician-assisted suicide could prevent some premature suicide because patients would know that they had control over the time and manner of their death.

## CONCLUSION

When the results of the vote in the Australian senate to repeal the Rights of the Terminally Ill Act were announced at 1 AM on March 24, 1997, the sponsoring senator hugged his wife, who was cradling their 3-week-old baby.<sup>5</sup> This is a powerful image—the defeat of “death” in the presence of a new life. At such times, an image like this may influence thinking more powerfully than carefully reasoned argument.

Autonomous persons will not have uniform opinions. In particular, people will differ and change according to age, religion, and circumstance. A democratic society that honors justice and liberty should acknowledge and permit these divergent opinions and allow dying people a degree of freedom in when and how the end comes.

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## Death Benefits

We have a small burial allotment  
set aside for cases like this,  
and a large American flag  
you can pick up at the office  
during working hours, or have sent  
to your home, but not in time  
for the funeral.

There is also a form to fill out  
in case he was orphaned, or damaged  
when young, or his mind  
took a turn for the worse — but only  
if the turn occurred in the war —  
in which case your loved one  
may get something else.

Sometimes survivors ask questions  
regarding what happened —  
Did my loved one have pain in the end?  
Could he have survived, if things  
had gone differently? We suggest  
you think twice before asking.  
These questions won't bring him back.

In summary, we did everything we could.  
We did even more than was expected  
of us. We worked double shifts, often  
without lunch, often half-sick ourselves.  
No one has ever cared for a person  
the way we cared for your loved one.  
Please accept our regrets.

Jack Coulehan

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